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ABSTRACT

Caring, as distinct from the physical surroundings and the social system in which it occurs, cannot be bought and cannot be professionalized. In addition, while caring is a vital element in dealing with psychiatric illness, it is both strenuous as well as unmeasurable, and thus more difficult to supply and finance than professional treatment or material care. Halfway houses, which now cover a great variety of facilities, try to provide a setting in which caring can occur. Small community care centers in Vermont exemplify the type of facility that provides a caring environment. These facilities are enriched by a social support system supplied by area community health centers. Unfortunately, the pressure of third-party payers has brought about a professionalization of staff as the halfway houses try to receive adequate financial compensation. As a result, the current third-party payment system is working to remove the element of caring from the very halfway houses designed to allow it. In order to rectify this situation, third-party payers must be convinced that caring is an essential ingredient in dealing with psychiatric illnesses, and that it must be provided by non-professionals even though this reduces the ability to provide quality control. (Author/EB)

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Caring, the Stepchild of Our Medical Care System

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The topic of my presentation is treatment, care and caring. We do not question the need to pay for the professional treatment of chronic psychiatric patients. In fact, third-party payers will pay for many treatments which have never been proven beneficial. In addition, material care is well financed, as anyone in need is supplied with room and board. Difficulties arise, however, in financing the social framework which a chronic psychiatric patient needs in addition to professional treatment and material care. This necessary social framework consists of a group of people with whom the patient is in daily contact, and who respond to the patient with simple interpersonal concern for the patient as a fellow human being. When such concern exists between people it is called "caring." And while "caring" is a vital element in dealing with psychiatric illness, it is both strenuous as well as unmeasurable, and thus both more difficult to supply and finance than professional treatment or material care.

The healthy individual maintains and adds to his own "caring" matrix beginning with the family in which he grew up, and during a short illness his social matrix supports him. Psychiatric patients with chronic illness have lost their social matrix and have an inability to maintain their own social matrix; and therefore, either for a short period of time or for the rest of their lives, need a social matrix ready-made for them.

What makes up a social matrix? First, a group of people with whom we interact over long periods, our relatives, the people we live with like our family, roommates, co-workers, and people we play with. Within this social matrix occurs participation in common tasks and games, sharing of values and loyalties, and caring, that human loving of another without demanding anything in return.

Years ago the old-fashioned boarding house supplied many psychologically disabled with a ready-made social matrix. You had your own room but you shared a living room and two meals a day with others and you could interact with them to the extent that you wished; a social group was always there. This boarding house is no more. In Vermont we have re-created two of them for long-term psychiatric patients. Such a boarding house functions best for patients who are able to work but need a social matrix to sustain them during the non-working hours of the week. In the boarding house situation, a social matrix is provided in which one guest caring for another can occur, and most of this caring goes on between different guests of the boarding home. The director of the home supplies the setting in which caring can occur. The social matrix is there even during times when the individual guest may not be able to play his part in maintaining it. As long as the matrix is provided, the guest can participate and survive. This matrix would not sustain itself from the participation of its members. A planned outside effort is essential for this social support system to survive.

Providing such "caring" is a strenuous task. First, these caring relationships are not controlled by appointments or eight-hour shifts. Caring does not go off duty. Let us look at the same dilemma in another field and different country. The original communist plan in Russia for child-rearing proposed that 80% of all children be raised in state-run homes which could see to it that the children received the scientifically correct physical, cognitive and emotional stimulation at the appropriate times. Maximum development would be guaranteed. The correct teaching of the values of socialism and patriotism would be assured. This program was abandoned. They were unable to supply an adequate substitute for parental caring, especially maternal caring. The

limitless commitment of mother to her child cannot be duplicated by a series of 40-hour-a-week workers.

Caring requires constant interaction between the provider and the person for whom he is caring. So a "caring" relationship is the complement of a professional relationship. One of the hallmarks of professionalization is that it limits the interaction between therapist and patient. The therapist administers treatment, be it for five minutes or for an hour. Good therapists are kind and considerate, but their professional relationship does not go outside the professional part of their lives. We do not bring our patients home to dinner. The caring relationship differs from the professional relationship also because caring involves taking risks. The family aspect of a caring relationship centers around the willingness to take risks. If misfortune occurs, the social network provides crisis intervention, without trying to measure and determine who should receive how much caring. But the very purpose of the professional relationship is to protect the therapist from such responsibility. And so, although mental health literature is filled with attempts to find professionalized ways of providing caring, I am convinced that this is a dream not to be. The professional role in this situation is, one, to make the decision that such a setting is needed, and, two, to see to it that it has stability over time. Caring cannot be institutionalized, but we can create institutions in which caring can occur.

The caring itself depends on nonprofessionals who utilize human qualities given to all of us. Our third-party payers pressure us to take these caring individuals and train them in some way to professionalize them

so that they can justify paying for their services, to make them part of the treatment team. But the more we professionalize them, the less they can provide the very caring for which we originally added them to the staff. Caring for the chronically ill is an exhausting business because one must continually give and only occasionally receive. The reason the professional has to limit his relationship is that he wants to live his own private life and must build protective walls against the encroachment of his treatment responsibilities into his private life.

In the ideal setting, a professional would decide what was needed, an administrator would provide the continuity of the setting, but the non-professional would provide the caring. There is another important reason for having nonprofessionals provide caring. While the patient relates to the professional as a parent figure, most commonly it is in the client's parental relationships that there have been the most long-standing unresolved problems. But if the person providing caring is a nonprofessional, the guest can relate to this nonprofessional more on a peer basis, and our experience indicates that chronic psychiatric patients can make better progress in peer relationships than they can in relationships with parent substitutes. Again, the nonprofessional can help the patient in a way not open to the professional.

At Spring Lake Ranch in Cuttingsville, Vermont, we have learned to utilize college student volunteers who come for three to twelve month periods to provide this kind of caring. Knowing that the commitment is time-limited, they can afford the kind of total involvement demanded of them. They can forego many personal freedoms for limited periods of time if they value the purpose. These students are not therapists, and their caring is not treatment. In the same way, our parents are not our therapists. These

young people learn a great deal about themselves and mental illness, but they do not become professionals. We give neither courses nor award diplomas. If we are to have an extensive system of halfway houses, who will do the caring? And who will pay for caring? Material care and professional treatment can be financed because they are susceptible to measurement and thus to quality control in some form.

Any chronic psychiatric patient needs basic physical care which can be standardized and supplied according to routine formula. This kind of basic care is measurable; one can train inspectors to visit the facilities where it is supplied and check on the quality of the housing, the quality of the food, the safety precautions, and the cleanliness. The measurable aspect of treatment is found in the professional qualifications of the therapist. As long as treatment is supplied by individuals with acceptable qualifications, whether they be as psychiatrist, social worker, psychiatric nurse, occupational therapy worker, recreational worker, dance therapist, art therapist, and many others, financing is obtainable.

The level of payment is related to the length and intensity of the training. The assumption is that all professionals use "the correct" treatment and that all treatment will have beneficial effects. With basic care, measurable physical conditions are checked for quality control, while with treatment, the professional qualifications of the therapist are checked. I believe we must learn to describe clearly what any halfway house provides; we must convince third-party payers that this caring is an essential ingredient in dealing with psychiatric illnesses, and that it must be provided by non-professionals even though this reduces the ability to provide quality control.

We might start this process by clearly defining different kinds of halfway houses.

The term "halfway house" is used in a very general way today and describes many different facilities. In a paper seven years ago, I described the many varieties of needed halfway houses. We need community care homes which take care of chronic patients of whom we have no expectations for improvement, but for whom we would like to provide the best life possible. We already have other community care homes which deal with patients who we hope may gradually improve further and perhaps someday leave the home. Obviously, these two homes require different methods of treatment and caring. The first is interested in stability over time, preventing undue stress and pressure on its guests, enriching their lives to whatever degree is possible. The second kind of home must continually try to push the guest beyond his previous plateau of adjustment, to challenge him with opportunities for higher levels of functioning, and to support him strongly when he makes any move forward. In supporting these forward moves, the homes take risks with their guests, like a family with children. So far we have not differentiated these two types of community homes, but I believe that the chronic patient put into a home which expects him to improve will have an unduly difficult time, while the patient who has the potential to improve, if placed into a chronic care home, is unlikely to realize his potential. There are homes that specialize in vocational rehabilitation, the teaching of social skills, easing the transition from hospital to community, etc.

Institutionalizing caring raises the problem of financing the houses that provide caring, and financing raises the problem of quality control.

Third-party payers are interested in quality control. Unfortunately, caring is something that is not measurable. Usually quality control becomes equated with control of the physical environment and professional treatment, the number of square feet per guest, the number of hours of professional time per day, the quality of records. This is the kind of thing an inspector can verify.

We must find ways to prevent valid quality control from rewarding material care and professional treatment only to the constant detriment of caring. In Vermont we are exploring the possibility of establishing new kinds of quality control standards. Under this system, community care homes beyond meeting minimum physical standards, would be asked to describe the program that they propose to carry on for their guests, and when inspected, the inspector would try to see whether the program described by the home itself was in fact being carried out. In other words, the community care home would be measured against its own standards. Initially, the home would present its proposed program for approval by the licensing authority.

Since true caring is as impossible to purchase as love, in the long run I do not believe that any insurance plan however generous, will be able to supply the needed caring by making money available. At best, money can allow the creation of settings in which caring might occur. It would be difficult to involve an insurance plan in providing caring itself because, as we have already mentioned, caring involves taking risks which entail legal liability. Third-party payers wish to minimize risk, and consequently don't want those providing caring to take chances. But a facility that supplies caring will by definition be taking risks, and risks which are probably uninsurable at

that. To a certain extent, of course, the nature of a halfway house is itself a form of protection because the caring environment tries to simulate the family, and hopefully family members do not sue each other. In the final analysis, however, just as caring itself cannot be bought, neither can its failures be absolutely insured against, and this fact together with the necessity to have caring provided by nonprofessionals, makes it hard to finance caring as part of a health insurance plan.

Caring is needed in many areas of our society. In the long run, I cannot see how we can meet our needs for caring unless we institute some type of generalized required work service for all of our young people where they would contribute one or two years to do those jobs which no one will do for money, whether they be working in areas of social isolation or in community care homes, in psychiatric hospitals, in hospitals for the chronically and terminally ill, with the poor and unfortunate of all types in our society and the drudgery of most routine military duty. The Peace Corps and Vista were attempts to provide caring by people who were willing to give a time out of their life for this purpose without the consideration of financial reward. Only by combining our care and treatment programs with this type of service program, can we add the caring element on any long-term basis to our programs for the psychiatrically disabled.

Disability pensions are a part of our care and social support system. Our present system of disability pensions ends up penalizing the disabled person who tries again and again. A client of mine was recently turned down for Social Security Disability because her earnings were too extensive. These

earnings had been produced with a fabulous support system supplied by many, many different individuals. The client would repeatedly get acutely paranoid at work and would have to call a member of the support system up and maybe spend half an hour being reassured and, so to speak, talked down. No one was financing this support system, but without it she would not have amassed the earnings which denied her her Social Security pension. As long as she is not receiving Disability, she also cannot obtain Medicaid. So she can afford to buy the medication which she needs only with financial help from her mother, but her mother is in her 70's and will not be able to do this for long. This client is an example of two flaws in our current system of health care financing. First, she is able to function only by virtue of a social matrix and support system which our current system will not pay for. The matrix which this client is using is voluntary, and there are limits to the extent of voluntary assistance. As a professional who must earn his living, I can only allow myself to start "caring" for a small number of my patients. The second flaw in our health care financing system illustrated by this example, is her inability to get a pension. The purpose of the treatment was to allow her to work normally. As soon as she succeeded in working, she was disqualified for the support which allowed her to continue working. In recent years that has been called "Catch-22." This client is an example of a voluntarily provided social matrix and social support system which allows this client to function, but which our present program, which only deals with care and treatment, will not finance. I believe we must find some system which would allow a person to go on a Disability pension, be allowed to earn to the extent that they were able, paying back some of their pension whenever they were earning well. But these people can earn only enough money to pay for

their physical care, and they cannot pay for the needed supportive social matrix which makes it possible for them to earn the money for their basic care. We must have a system which makes it possible to supply the supportive social matrix which in turn allows these people to work at simple jobs. Community mental health was to supply much of this social matrix, but it has gone the route of professionalization, so it cannot supply caring. The early indigenous workers were nonprofessionals; they provided caring for ghetto clients. They were quickly turned into paraprofessionals, who are low-priced professionals.

Of course, one of the saddest experiences is to work with a chronic psychiatric patient to the point where they could handle some simple job only to find that the unemployment situation is such that it is totally unrealistic to expect an employer to give a job to our handicapped individual. Perhaps it is time that we passed a law similar to the one in England which requires all employers of more than a certain number of employees to always have amongst these employees a certain percentage of the severely handicapped. Further, some of our clients cannot work a forty-hour week, but two or three of them between them could maybe handle a job. In Canada some factories have started to allow women with children to share jobs between them. The two women promise to cover the job completely and then divide the hours up between them to their convenience. This kind of arrangement would allow our clients who occasionally cannot deal with ordinary stress to take some time off without losing their job.

What is the size of our problem? In Vermont at the present time we have 2000 psychiatrically disabled people in community care. This covers both the

chronic psychiatric patient and the mentally retarded. Most of these are in small private community care homes. The population of the state of Vermont is 440,000, and an extrapolation from these figures for the country-at-large would tell us that we need to provide community care for approximately one-half million people. How should this be done? A caring environment tries to come as close to the model of a well-functioning family as possible. A home staffed by three shifts and relief personnel obviously cannot do this. Most of our homes in Vermont are private, run by people who make our clients members of their extended family. The people who run these homes are not professionals; they have had no special training, but the caring I observe as I provide the after-care for these clients is heartwarming. Vermont is a rural state, and perhaps what we are doing is feasible in a rural area where distance from others, privacy and opportunities for simple outdoor activities are easily available. In many of these homes one member of the family carries on with an outside job or perhaps the family runs a farm. Since the community care homes are only paid for physical care and not for caring, the enrichment provided by social and recreational activities must be provided from other sources, and at the moment is provided by payments for treatment for this reason and provided by a variety of professionals. The community care homes should be supplemented by an enriching social support system supplied by the area community mental health center. This social support system provides recreational and social activities. The caring itself is provided gratis by the operators of the homes. The private community care home keeps costs at a very low level since the primary operators do not work on a 40-hour week and have such a small number of clients that they can truly know them, can be caring, and can individualize their programming. The community mental health center also continually monitors the community care homes,

arranges for vocational training or job placement when indicated. It also helps clients change homes if they are dissatisfied or mismatched.

Using the support of community mental health centers, the isolation of a chronically ill psychiatric patient in a community care home can be offset. Given that this possible isolation is offset, the opportunity for caring provided by the small care home makes it a good alternative to hospitalization.

For a community care home to function as we have suggested, it must obviously be able to control its admissions. It must be allowed to specify the kind of client it can best work with and to see to it that those are the clients it receives. It is tempting sometimes with community care homes to do the same thing that welfare departments do with unusually good foster homes. They gradually load them with more and more problem cases until the foster home or the community care home completely collapses or deteriorates and must be closed down. We ask them for caring beyond their capabilities. Our capacity for caring is limited, so ways must be found to prevent the pressures of the moment to lead to over-loading.

The common splitting of the financial responsibility for physical care and professional treatment leads to a complication. Although the agency responsible for treatment would like to prevent re-hospitalization and would be willing to make some extra effort to achieve this when a client decompensates, physical care home receives no extra rewards for taking care of someone during an acute episode of disturbance, and therefore feels put upon if it is asked to do so, and feels that when someone decompensates they should be allowed to send this client back to the hospital. Perhaps this problem could

be handled by having the community mental health center provide some staff support to the community care home while it is dealing with a decompensated patient.

In summary, the halfway house now covers a great variety of facilities from a boarding home at one extreme to a small chronic care facility at the other, from family homes with two or three guests to mini-institutions under public auspices. Unfortunately, the pressure of third-party payers has brought about a professionalization of staff as the halfway houses try to receive adequate financial compensation. Money is certainly absolutely necessary to provide the social systems in which caring can take place. But as we have tried to indicate, one of the most important contributions the halfway house can make to the care of the chronic psychiatric patient is to provide a setting in which caring can occur, and caring itself, as distinct from the physical surroundings and the social system in which it occurs, cannot be bought and cannot be professionalized. So the current third-party payment system is working to remove the element of caring from the very halfway houses designed to allow it.

Whether caring on a massive scale for the 500,000 individuals for whom we must provide community care can ever be provided without a national work service, I am not prepared to say. In the fields of nursing and of social work, we have seen the same kind of pressure to professionalize. Florence Nightingale started nursing to add caring to the treatment of battle casualties. And while nursing consisted mostly of personal sacrifice, the nurse used to be truly wedded to her job. She has now become highly professionalized and has become one of the large group of therapists. Nuns and monks provided

caring through a lifetime of service. We keep adding new nonprofessionals to the treatment team to provide the caring, while economic necessity soon teaches them to professionalize themselves in some way to improve their pay, leaving the patient again without anyone who can concentrate on just caring. No one will tackle a lifetime of caring. The job can only be done if everyone gives a period of their life over to caring.

The small private community care home can provide physical care and caring at a very low price. As soon as the community care home becomes an institution with a 40-hour work week, its costs will begin to equal those of most hospitals and the caring will again disappear. We must learn to distinguish many different types of community care homes, and we must not let quality control end up as an overemphasis on the measurable aspects of the physical setting and professional treatment, again making caring the neglected stepchild of our programs.

Our goal should be to provide social settings in which each client will experience at least one caring relationship. We will need research to help us with this task.

Insurors pay for much social support in the guise of treatment, even though Dr. May's studies indicate that only basic social support like help in finding housing and jobs affects long term outcome. They pay for questionable treatments because they are professionally standardised. There are many after-care programs where third party payers finance social, recreational, and occupational programs without even asking the question of how much is needed. We demonstrated sixteen years ago that minimal social support and enrichment can reduce recidivism for chronic psychiatric patients as much as the fancy programs of today. Could we dream of using the money now going for unwarranted enrichment to make possible the provision of caring?

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